

**Systemic Development of the Family Caregiver Support Program:
Considerations for the Service Package**

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The **Project Advisory Committee**, made up of State Unit on Aging Directors, provides ongoing guidance to the project and contributed to the development of this document. The committee was chaired by Sue Ward, NASUA 1st Vice President and Secretary of the Maryland Department of Aging. Members included: Richard Browdie, former Secretary of the Pennsylvania Department of Aging; Lillian Glickman, Secretary of the Massachusetts Executive Office of Elder Affairs; Kathy Leitch, Assistant Secretary of the Washington Aging and Adult Services Administration; Donna McDowell, Director of the Wisconsin Bureau of Aging and Long Term Care Resources; Eileen O'Connor, Assistant Commissioner of the New Jersey Division of Senior Affairs; Lynda Terry, Director of the California Department of Aging; and James Varpness, Executive Director of the Minnesota Board on Aging.

The **Expert Panel on the Service Package** gave freely of their time and expertise, made recommendations regarding the systemic development of the service package and reviewed the draft Guide. Members of the Expert Panel included: Lynn Friss Feinberg, Deputy Director of the Family Caregiver Alliance; Ken Hepburn, Ph.D., Director of the Aging and Geriatric Medicine Program at the University of Minnesota School of Medicine; Kathy Leitch, Assistant Secretary of the Washington Aging and Adult Services Administration; Angela Heath, representing the National Association of Area Agencies on Aging; Jonathan Lavin, Executive Director of Suburban Area Agency on Aging; Dan McGuire, Director of the Bureau of Home and Community Based Services at the Pennsylvania Department of Aging; Rhonda J. V. Montgomery, Ph.D., Director of the Gerontology Center at the University of Kansas; Kathleen O'Brien, Vice President of Program Services at the Alzheimer's Association; Andrew Scharlach, Ph.D., Kleiner Professor of Aging at the University of California at Berkeley; Samuel Simmons, President and CEO of the National Center and Caucus on Black Aged; Marta Sotomayor, Ph.D., President and CEO of the National Hispanic Council on Aging; Sue Vaeth, Manager of the Senior Care Program at the Maryland Department of Aging; Steve Wilson, President of the National Title VI Directors Association; and Donna L. Yee, Executive Director of the Asian Community Center.

Bernice Hutchinson, NASUA Senior Project Manager, organized the Advisory Committee and the Expert Panel and planned the meetings of both groups. Gregory Link, NASUA Program Associate, developed the state profiles. Both Bernice and Greg contributed ideas and suggestions that were incorporated in the Guide.

FOREWORD

This Guide is the first in a series of publications designed to assist states to consider the Family Caregiver Support Program (FCSP) as part of the broader long term care infrastructure in the state - including Medicaid, Older Americans Act, and state-funded home and community based service (HCBS) programs, as well as state-supported caregiver support programs that exist side-by-side with the FCSP. A *systemic approach* to program development is an intentional, step-by-step method designed to bring the system components of the FCSP - service package, coordination, continuity, quality and effectiveness - into a coherent whole. A systemic development approach will result in state FCSPs that are accessible; flexible; consumer-directed; culturally-competent; and integrated with HCBS programs. FCSPs with these characteristics are more likely to provide caregivers with customized services and support.

Each Guide in the series will focus on one or more of the system components identified above. An Advisory Committee, composed of State Unit on Aging representatives, provides ongoing guidance and support to the project. NASUA will convene an Expert Panel, made up of practitioners, administrators, policymakers, advocates, researchers and educators in the fields of aging and caregiver supports, to develop recommendations on each system component.

This Guide focuses on the FCSP service package. It is designed to provide states with the tools and strategies to both develop the FCSP infrastructure and make the connection between the FCSP and HCBS programs. Critical questions related to the service package are identified, and program design approaches and optional implementation strategies for addressing each question are explored. A summary of nine state caregiver support programs, identified by the Expert Panel as states where the FCSP is being developed as part of the HCBS system, is provided in the appendix. A companion document, "Research Briefs on the FCSP Service Package," summarizes relevant research and descriptive studies of caregivers and caregiver supports. These materials provided background and were used to inform the discussions of the Expert Panel on the Service Package.

All publications developed under this project, including this document, may be downloaded from the NASUA web site at www.nasua.org.

Systemic Development of the FCSP: Considerations for the Service Package

PART I INTRODUCTION

The aging network has always realized that it has two clients--the care recipient and the caregiver. Now the NFCSP makes that clearer.

Older Americans Act programs have long recognized caregivers as key players in meeting the needs of older persons in the community. The creation of the National Family Caregiver Support Program (NFCSP)¹ in the 2000 Reauthorization of the Older Americans Act for the first time requires all State Units on Aging (SUAs) and Area Agencies on Aging (AAAs) to focus on the caregiver - rather than the older consumer - and provide services primarily for the benefit of caregivers themselves.

The NFCSP is intended to offer a "multifaceted system" of caregiver supports, that includes, at a minimum, the following services: **information; assistance; individual counseling, support groups and caregiver training; respite care; and supplemental services** "on a limited basis, to complement the care provided by eligible caregivers."²

Two population groups are to be served by the program: family caregivers and grandparent or older relative caregivers of children. The **family caregiver** is defined as "an adult family member or another individual, who is an informal provider of in-home and community care to an older individual." A **grandparent or older individual who is a relative caregiver** is "a grandparent or stepgrandparent of a child, or a relative of a child by blood or marriage, who is 60 years of age or older and...lives with the child; is the primary caregiver of the child because the biological or adoptive parents are unable or unwilling to serve as the primary caregiver of the child; and has a legal relationship to the child, such as legal custody or guardianship, or is raising the child informally."³

A handful of states funded comprehensive support programs for caregivers prior to the enactment of the NFCSP. Even so, whether the SUA previously administered a state-funded caregiver support program for several years or the FCSP represents the first time the SUA has focused specifically on the needs of caregivers, all State Units on Aging have had to address a variety of policy issues and ensure that there is a basic structure for the NFCSP. Operational definitions have been developed for the components of the service package. States have decided whether or not to require all areas of the state to use up to ten per cent of their caregiver dollars to support grandparent and other kinship care of children (as allowed under the Older Americans Act) or to permit area agencies on aging to decide on the target population for their programs. Any limits on services - e.g., setting a maximum number of hours of respite care which may be provided in a month - have been set or are still being considered. Likewise, funding

¹ "NFCSP" will be used to denote the National Family Caregiver Support Program in this paper. "FCSP" will be used when discussing state or local programs that are part of the NFCSP.

² Older Americans Act, Title III, Part E, Section 373, (b).

³ Ibid., Title III, Part E, Section 372.

allocations among the components of the service package have been decided either at the state or area agency level.

Wisconsin has developed written policy requiring coordination of the FCSP with HCBS and voluntary organizations that serve caregivers. The FCSP is viewed as "an opportunity to advocate with other provider agencies to expand and enhance existing services to better meet the needs of caregivers."

The National Family Caregiver Support Program provides State Units on Aging with a unique opportunity to build and enhance support for older persons and their families. Older Americans Act and Medicaid-financed programs have made great strides in recent years in helping millions of Americans with disabilities of all ages to remain independent as long as possible. Now, the NFCSP adds a key piece to the package of services available. Furthermore, with its emphasis on building "multi-facted systems of support for families," the FCSP can expand the scope of state long term care systems.⁴

The creation of the NFCSP occurred at a pivotal moment in the history of long term care. During the past twelve years, a plethora of events - the 1990 enactment of the Americans with Disabilities Act, the Supreme Court's decision in the *Olmstead* case in 1999, Secretary of HHS Donna Shalala's January 2000 letter to the Governors followed by a series of letters from the Health Care Financing Administration (now CMS - the Centers for Medicare and Medicaid Services) to State Medicaid Directors advising states to develop "Olmstead Plans" to facilitate community living for persons of all ages, President Bush's "New Freedom Initiative", the awarding of "Systems Change" grants in the fall of 2001 followed in March 2002 by additional grant award announcements - have dramatically and forever changed the landscape.

To be most effective, the Family Caregiver Support Program must become a highly visible, readily identifiable program that responds to the diversity of caregiver needs, while at the same time forging connections to the home and community based services (HCBS) system in each state. Since it is unlikely that the FCSP alone will be able to meet the needs of all caregivers or respond to all the needs of an individual caregiver over the length of his/her caregiving career, it is vitally important to ensure the efficient and economical use of limited Older Americans Act (OAA) funds and to take advantage of other services that may support caregivers and help meet the needs of care recipients.

⁴ Claude Allen, Deputy Secretary of the US Department of Health and Human Services, speaking at the September 2000 National Family Caregiver Support Program National Conference, convened by the Administration on Aging.

The Leadership Role of SUAs in the HCBS System

State Units on Aging are in an ideal position to bring family caregiver support to the forefront of state policy discussions and build needed support in the states for the FCSP. In recent years, SUAs have taken on the administration of a broad range of home and community based services, including Medicaid waiver programs and state-funded home and community based service programs, and are recognized as leaders of HCBS program development and as advocates for alternatives to institutional care. SUAs have played a pivotal role in the development of state *Olmstead* Plans, are key players in putting together coalitions of stakeholders, and are playing a leading role in many of the "Systems Change" grants funded by CMS. SUAs also bring to the table a perspective grounded in the Older Americans Act principles of independence and dignity for older people and experience as both advocates and administrators.

Integrating the NFCSP into the HCBS system

The dilemma is how best to coordinate services and processes without losing the independent identity of the caregiver support program.

The focus of HCBS programs is on serving persons with disabilities. However, there is an increasing realization that services for persons with disabilities will not work without the family caregiver's support. Family caregivers do not relinquish their responsibilities when "formal" services become available for their loved ones. In fact, the services provided by caregivers are the underpinning of the formal HCBS system, but until now, caregiver supports have largely been ignored in the development of these services.

Better approaches are needed to ensure that the FCSP and available home and community based services are mutually supportive and work together to meet the family's needs. To maximize the effectiveness of the FCSP, states should build on the existing home and community based services infrastructure - including state-funded caregiver programs, other aging services programs, and the full range of HCBS programs. Collaboration and coordination between FCSPs and HCBS programs is more likely to produce a long term care system that addresses the needs of both caregivers and care receivers.

FCSPs will benefit from the knowledge and more than twenty years' experience of HCBS programs developing structures for a coordinated service *system*. More importantly, consumers will benefit from the creation of a more understandable and user-friendly system that incorporates caregiver support into the broader HCBS framework. Information sharing within and across programs can only enhance the FCSP and should include knowledge exchange about promising practices and optional approaches at both the state and local levels.

PART II SYSTEMIC DEVELOPMENT OF THE SERVICE PACKAGE

*"The goals of system development should promote seamless services,
lead to efficient use of resources, and achieve positive outcomes."*

Lynn Friss Feinberg

Family caregiving is a partnership - of the caregiver and the care receiver first of all - that ultimately includes health care providers, family, friends, neighbors and other natural supports and service providers.⁵ A systemic development approach to the FCSP supports this "partnership" notion. The package of services provided by the Family Caregiver Support Program should enhance and extend the caregiving situation and other formal services that may be provided to the care receiver and the caregiver.

In designing the Family Caregiver Support Program, both Congress and the Administration on Aging have set a clear expectation that the FCSP will do more than simply provide respite care, but will offer a package of services and supports responsive to a wide range of caregiver needs. The Older Americans Act describes the array of caregiver support services for "eligible caregivers" as follows:

- 1) "*information...about available services;*"
- 2) "*assistance...in gaining access to services;*"
- 3) "*individual counseling, organization of support groups, and caregiver training...to assist the caregivers in making decisions and solving problems relating to their caregiving roles;*"
- 4) "*respite care to enable...caregivers to be temporarily relieved from their caregiving responsibilities;*" and
- 5) "*supplemental services, on a limited basis, to complement the care provided by ...caregivers.*"⁶

Issues related to the systemic development of each service in the **service package** are identified and discussed in this section. In addition, key issues which may impact the entire service package are discussed. These issues include: accessibility of caregiver services; underserved populations; program flexibility; and consumer direction.

Accessibility of Caregiver Services

The development of Family Caregiver Support Programs that effectively reach out to the diversity of caregivers who live in the community and respond to the wide range of caregiver needs is a formidable challenge facing states. According to the research, caregiving is a very individual function. Caregivers' needs are difficult to predict, even though some generalizations can be made - e.g., spouses generally provide more care than daughters or sons, female caregivers tend to provide more hands-on care, minority caregivers typically provide more care than whites. Perhaps equally important,

⁵ Andrew Scharlach, Ph.D., "*Meeting the Needs of Family Caregivers.*" Presentation given at the Annual Meeting of the National Association of State Units on Aging, June 25, 2002.

⁶ Older Americans Act, Title III, Part E, Section 373, (b)(1-5).

many individuals who provide care for their loved ones do not identify themselves as caregivers.⁷

Access to services is key to all home and community based services, including caregiver supports. The best designed FCSP will not be helpful to anyone if too few caregivers know of its existence or fail to see caregiver services as potentially helpful to them. The need to reach people who care for their loved ones but who do not always identify themselves as "caregivers" is a particular challenge for the FCSP. No less important is the need to ensure that caregivers get the assistance they need and want - for themselves and the care recipients for whom they provide care. Coordination and linkage of the FCSP and other HCBS programs are key to assuring access and reaching caregivers, as is developing partnerships with business, religious, ethnic, social services and community organizations.

Underserved Populations

Diversity is the strength of America. But many immigrant groups and minority populations remain isolated by poverty, language barriers, and other hurdles that inhibit full participation in American life. Family caregivers in these groups may face severe difficulties in caring for their loved ones. Cultural identity influences an individual's willingness to seek and accept help. For many ethnic and minority groups, family ties are very strong. In some cultures, it may be considered inappropriate to ask for assistance or to acknowledge that caregiving might be burdensome. In such situations, a focus on the family and the care recipient's needs is necessary.

It is likely that a broad range of cultures and ethnic groups will be found in any state and that individual communities in the state will contain unique racial, ethnic, cultural and religious groupings. Therefore, a one-size-fits-all solution will not work. State leadership is needed to ensure that the issues of culture and ethnicity are recognized and addressed in all parts of the state, while at the same time permitting each AAA to find the solution that works best for them.

Flexibility

States must ensure that the FCSP responds to individual caregivers' needs and preferences. However, deciding how much flexibility to allow in the program can be a difficult balancing act for states. The Older Americans Act is clear in the expectation that no matter where in the country caregivers live, they should have access to the same package of services. However, within these broad service categories, states are expected to design programs that are tailored to divergent community needs, as well as the varied needs and preferences of particular caregivers.

Each State Unit on Aging must decide how much flexibility to give Area Agencies on Aging to encourage the development of local variability in the program

⁷ Sharon Tennstedt, PHD, "Family Caregiving in an Aging Society." Presentation at AoA Symposium: Longevity in the New American Century, March 29, 1999, pp.3-5.

reflective of each community's needs and preferences, while at the same time ensuring caregivers access to a high quality, readily identifiable program of supports no matter where they live in the state.

Consumer Direction in Caregiver Programs

To assure a tailored response to each individual caregiver, the FCSP may choose to adopt a consumer-directed approach. A philosophy of consumer direction assumes that informed caregivers are able to decide for themselves what kinds of supports they need. A consumer-directed FCSP might give vouchers to caregivers, who may then use the vouchers to pay for the services and supports they need. These may be as wide-ranging as having a ramp built to accommodate the care recipient's wheelchair or bars installed in the bathroom; paying for an exercise class as a way to relive the caregiver's stress; or compensating a neighbor for spending the night with the care recipient while the caregiver visits family or friends.

If the FCSP is reluctant to use vouchers, more choices and opportunities for caregivers to make decisions about the supports they need still may be introduced in the program. Permitting caregivers to select neighbors or friends as providers of respite care and allowing caregivers to accumulate respite hours to use for a longer stretch of time are two additional examples of using consumer-directed approaches. States and AAAs may choose to define caregiver supports very broadly to include services not found on a typical caregiver support menu such as those listed above. Experts point out that what caregivers most need or want is often surprising to the professionals in the program. Given the variability of caregiver needs, it is unlikely that any program will be able to anticipate every possible service caregivers might want.⁸

1) INFORMATION

Information is defined as "group services, such as public education."⁹

Ensuring access to caregiver and long term care information and marketing the program are encompassed in the above definition. Also included in the information component of the FCSP are: outreach activities; development and dissemination of educational materials; convening workshops for caregivers; participating in public meetings and events; and using media outlets such as TV, radio and the internet (including the development of web sites) to reach caregivers.

While the other services in the OAA-mandated service package may be targeted to caregivers with particular needs, it is assumed that all caregivers need information - about the state's long term care system, about home and community based alternatives to institutional care, about caregiver support services and a myriad of other issues. Without

⁸ Dan McGuire, Pennsylvania Department of Aging and Member of NASUA's Service Package Expert Panel.

⁹ Administration on Aging, Data Collection and the National Family Caregiver Support Program. Shared with AOACARENET, June 11, 2001.

information, caregivers will not be able to obtain entry into the formal service system for themselves or for care receivers. Getting information to caregivers early and helping them recognize that they are indeed "caregivers" must be one of the goals of this program. Information is not only a *universal* caregiver service, it is the *pivotal service* provided by the FCSP.

Ensuring that the FCSP reaches the caregivers who are most in need of support is no small challenge. Crafting messages for families and friends who are providing care for loved ones to help them recognize that they are "caregivers" and that support services could be beneficial will require careful thought. Added to that is the challenge of reaching persons from diverse ethnic and racial backgrounds whose views of caregiving reflect unique cultural perspectives. How to market the program, and ensure that the marketing is effective are basic issues that should be addressed early in the program's development.

"Branding" the state's Family Caregiver Support Program to ensure that the program is readily identifiable as a source of caregiver assistance is worth considering. Such an approach can be effective in reaching large numbers of caregivers, and help persons who are providing care to relatives and friends to identify themselves as "caregivers" and the FCSP as a source of assistance. A statewide campaign aimed at most caregivers is more likely to assure that information about the program is consistently presented. This approach makes more efficient use of limited resources, but can still allow local programs to put their own imprimatur on the program.

Outreach strategies to reach caregivers might include: convening focus groups; holding public forums and conferences; putting information ads in newspapers; using the internet, radio and TV; and setting up telephone access lines with toll-free numbers. Many organizations and people in communities throughout the state have an interest and stake in the well-being of caregivers and their ability to continue their vital role in family and community life. To reach caregivers, it is necessary to connect to a wide variety of organizations and individuals - including physicians and other members of the medical community, businesses with employees who are caregivers, community organizations, social service agencies, and other governmental agencies - all of whom are likely to be in direct contact with caregivers.

The research indicates that caregivers are most likely to contact the formal service system to obtain assistance for the person for whom they provide care rather than for themselves. Therefore, a critical issue facing the FCSP is the difficulty caregivers face in obtaining information. In designing the information component of the FCSP service package, it is essential for states to consider the effectiveness of the Aging Information & Referral/Assistance program. Depending on how successful this already-established program is in reaching older persons and their families, the FCSP may decide either (1) to forge a close connection to the program; or (2) to serve as a catalyst for improvement or overhaul of the current information system. Whatever the situation, coordination between the FCSP and the I&R/A program is vital to ensure the success of both programs in reaching older persons and is the best remedy for ensuring that no consumer or

caregiver "falls between the cracks." However, forging this connection is not without pitfalls. The NFCSP is a new program with specific earmarked funds. SUAs and AAAs must consider carefully how to maintain the program's distinct identity, but at the same time connect the FCSP to already existing information services and service access points.

2) ASSISTANCE

Assistance is defined as "individual one-on-one contact, such as Information & Assistance or case management."¹⁰

Information alone is not assistance; however, it may not always be clear where the one ends and the other begins. Some caregivers who contact the FCSP will want only to be pointed in the right direction to obtain contact information for public and private service providers available to help their loved one or themselves. Other caregivers will need more. The range of assistance needed by caregivers may include:

- Someone to make a referral on the caregiver's behalf to a public or private program;
- A caregiver specialist or case manager to assess the caregiver's needs and develop a plan for providing supports;
- A case manager to guide the caregiver through the series of steps required to obtain needed services for the care recipient (i.e., screening, completing an assessment of needs, developing a care plan and monitoring/follow-up).

Providing assistance to caregivers can be time consuming and requires a considerable commitment of staff and resources. Adding complication to this process is the fact that caregivers' needs are apt to change over time, especially as the needs of the care recipient change. Caregivers may need assistance on an ongoing basis or from time to time. Thus, the assistance component of the FCSP must be tailored to fit diverse and changing caregiving situations.

The home and community based service system in most, if not all, states has come to rely on the assessment process as a way to obtain in-depth information about the consumer's situation. Assessment is a way to gauge the consumer's service needs and to identify the tasks the consumer is able to perform her/himself. The presence of a family caregiver who provides assistance on an ongoing basis is typically taken into consideration when the service plan is developed.

A *caregiver assessment* provides one avenue for identifying both what is working - and what is not working - in the caregiving situation, and may include an evaluation of the caregiver's stress level or "caregiver burden." In developing the assessment component of the FCSP, states should consider the merits of adopting a formal assessment instrument and identifying which instrument will best meet their needs.¹¹ Whether or not a formal assessment instrument is adopted by the program, FCSPs should

¹⁰ Ibid.

¹¹ The Administration on Aging has collected a number of examples of caregiver assessment instruments currently being used by FCSPs, and has posted this information on its Web site at www.aoa.gov.

put in place a process for determining caregivers' needs. It is also essential for the FCSP to ensure that the agencies and organizations that serve as the entry point(s) for HCBS know about the FCSP and make referrals to the program when caregiver needs are identified.

The information gathered during the assessment typically forms the basis for development of a service plan. While it will not be appropriate or necessary to develop a service plan for all caregivers who come to the FCSP, there are situations when the service plan is essential, usually when certain interventions such as respite care are used and/or to coordinate FCSP supports for the caregiver with home and community based services provided to the care recipient. Service planning may serve as a vehicle for setting goals related to provision of a particular service, tracking progress and/or identifying the outcome of a particular service intervention.

*In **Oregon**, the AAAs serve as the entry point for both older consumers who need HCBS and caregivers who need FCSP services. Case managers complete an assessment and determine the program that is most appropriate for meeting the needs of both parties.*

To most effectively serve the needs of the family unit - the caregiver as well as the care receiver - the public long term care system must ensure a response to the needs of both no matter where either party enters the system. Given the limited resources of the FCSP, building a connection to information and access points that are already in place makes it much more likely that the FCSP will reach the caregivers it was created to serve. Thus, states such as Pennsylvania have incorporated caregiver assessment into the comprehensive assessment for home and community based services. Other states have developed an assessment solely for caregivers to be administered by the FCSP, reasoning that caregivers are less likely to openly identify their own needs when the care receiver is present.

***California** requires all caregiver resource centers to hire bilingual staff and provide information and educational materials in languages other than English.
The State of **Washington** will use administrative funds to support pilot projects to serve three underserved groups: ethnic communities; geographically isolated/rural communities; and ethnic kinship caregivers.*

The type and amount of assistance that caregivers need and want will vary from person to person. It is vital that the program be developed with due consideration for differences in the types of caregiving situations, as well as cultural and ethnic differences. To meet the diverse needs of caregivers, FCSPs are advised to develop alliances and working relationships with community organizations that represent the diversity of the population, including disability organizations, organizations that serve children, as well as specific cultural and ethnic organizations. Staff training to recognize differences in cultural perceptions of caregiver support needs and special recruitment efforts aimed at particular segments of the population also should be considered.

A number of SUAs and AAAs have developed staff positions to handle the assistance component of the FCSP.

- The Carroll County, Maryland AAA employs a *senior care/family support services coordinator* who, among other duties, provides case management for both consumers of the state-funded Senior Care Program and for caregivers served through the FCSP.
- Seventeen of North Carolina's AAAs employ a *regional caregiver specialist* who collaborates with a wide array of individuals and groups to develop community resources and coordinate care for caregivers.
- Several AAAs in the State of Washington have developed a *family caregiver/resource specialist* position responsible for conducting assessments, providing consultations and assisting caregivers to gain access to needed services.

3) COUNSELING/SUPPORT GROUPS/CAREGIVER TRAINING

Counseling/Support Groups/Training is defined as "provision of advice, guidance and instruction to caregivers in an individual or group setting."¹²

Counseling caregivers may include individual or group counseling provided by professionals, as well as assistance with individual problem-solving. ***Support groups*** may focus on providing information to caregivers (e.g., regarding community resources, specific disease processes or disabilities), providing emotional support or a combination of the two approaches. ***Education and training*** may involve teaching problem-solving skills or coping techniques that help the caregiver deal with everyday issues in the caregiving relationship, or providing instruction in certain kinds of caregiving tasks.

The SUA may set qualifications, training and experience standards for FCSP counselors, support group facilitators and caregiver trainers for the entire program or require AAAs to set their own standards. In some states, counseling and training for caregivers are provided directly by AAA staff. For example, Minnesota's *caregiver consultants* work directly with caregivers to educate, train, provide emotional support, and link them to services. FCSPs that have chosen to provide counseling and support group services through private contractors typically develop and provide education and training for providers, as the Suburban AAA in Illinois does.

Soliciting the opinions of caregivers themselves and coordination with organizations that serve particular ethnic or religious groups are necessary first steps in developing these services. The stigma attached to counseling, perceived as akin to psychotherapy, remains strong in American society and must be taken into consideration by FCSPs. Furthermore, counseling/support groups/training may raise significant diversity issues. Some ethnic groups are more reluctant than others to take advantage of

¹² Ibid.

one-on-one counseling, especially if the service is provided by someone whose culture or ethnic background is different from their own. Even when all participants in a support group share the same culture and/or ethnic background, there still may be considerable reluctance to participate.

By contrast, caregiver training may be perceived more positively as a way for caregivers to learn to do a better job. Education and training may be provided in a group setting, one-on-one in the caregiver's home or via the internet. Electronic media such as videos may also be used to educate caregivers at a time and place most convenient to their needs. Creative use of videotapes, computers and other technologies to offer training in the caregiver's home and at his/her convenience may extend the program's resources in this arena, as will taking advantage of training programs that already have been created by community organizations such as the Alzheimer's Association, mental health agencies and disease-specific organizations. Both approaches may enable the FCSP to do more with limited resources.

4) RESPITE SERVICES

Respite services are defined as "temporary, substitute supports or living arrangements to provide a brief period of relief or rest, such as in-home respite, adult day care or institutional respite on an intermittent, occasional or emergency basis."¹³

Respite care has long been recognized as a vital caregiver service. In developing the respite care portion of the FCSP, states are challenged, within the constraints imposed by limited budgets and the expectation that the Family Caregiver Support Program not be solely a respite program, to assure that caregivers who need respite are able to get this valuable service.

Studies have shown that getting respite to caregivers early in their caregiving experience will do more to relieve stress and other problems than offering respite services after the caregiver has been providing care for many years. Therefore, getting respite care to the *caregivers most in need* is crucial to the success of caregiver support programs. Typically, an assessment of caregiver and/or care recipient needs is done when respite is requested. Most states and AAAs have set specific eligibility criteria for respite care, such as requiring that the care receiver need assistance with a set number of ADLs or establishing a minimum score that caregivers must achieve on a standard "burden scale."¹⁴

The FCSP's definition of respite care is broad, encompassing a variety of service settings and delivery modes. A too narrowly drawn definition that limits respite to a particular setting - such as adult day care - or that requires respite care providers to meet licensure or certification requirements may, in fact, make respite unappealing and unavailable to the caregivers who are most likely to need it. Respite that may be

¹³ Ibid.

¹⁴ See 2) **Assistance Services** for a discussion of caregiver assessment.

provided only at certain times of the day or on specific days may not respond to the diversity and unpredictability of caregivers' needs.

Maximum flexibility and consumer responsiveness may be assured through adoption of a consumer-directed approach to respite care, which might allow consumers to use individual rather than agency providers or provide caregivers with cash or a voucher to be used to purchase a range of supports and services. The Pennsylvania FCSP, for example, provides a set monthly cash reimbursement to caregivers for all services. Although Pennsylvania allows funds to be used to purchase respite, home modifications/repairs, assistive devices or durable goods, it is reported that the majority of families use their cash reimbursement to purchase respite services. Other states may set a monthly cap for respite care only.

Respite care was probably the most widely available caregiver service prior to the passage of the NFCSP. States provide respite care through state-funded programs, as a service provided under Medicaid home and community based waiver programs, and through federally funded demonstration projects such as the Alzheimer's Demonstration grants. Innovative methods have also been used to fund the service, including private grant monies, tobacco settlement funds and in New Jersey at least, casino revenue funds. SUAs and AAAs should also consider partnering with Faith in Action projects funded by The Robert Wood Johnson Foundation, to complement and enrich the package of supports available to caregivers.

To the greatest extent possible, respite care provided under the FCSP should complement any respite programs that already exist. The fact that respite programs that pre-date the FCSP may serve different target populations than the OAA program must be considered. For example, a state's HCBS waiver program may target caregivers of persons with disabilities regardless of age or a state-funded respite program may serve specific groups of caregivers, such as those who care for persons with dementia. Coordinating the FCSP with one or more respite programs in the state will help to ensure that the greatest number of caregivers possible receive needed respite care, while at the same time preventing duplication and inappropriate overlap of services. Several states are addressing this issue:

- Massachusetts coordinates the services of the state Home Care and Respite Care Programs and the Massachusetts Family Caregiver Support Program through collaboration between the AAAs (which administer the FCSP) and the Aging Service Access Points (which administer the state-funded respite program). Either the AAA or ASAP serves as the single intake point for home and community based services for older people in each community. A "caregiver intake form" is completed when caregivers needing services are identified and a referral is made to the most appropriate program.
- In New Jersey, AAAs are required to develop a plan for coordinating the Statewide Respite Care Program (SRCP), administered by local New Jersey EASE sites, with

the FCSP.¹⁵ Under the plans, protocols must be developed by each county AAA and SRCP describing how caregivers entering either program will receive coordinated services. The protocols address such issues as referrals, information-sharing, service plan development and as needed, primary responsibility for case management. As part of the state's AoA-funded Innovation Grant, caregiver screening, assessment and service planning tools are being developed for use in all caregiver programs and policies are being developed on coordination of caregiver services. It is expected that future policies will address issues such as priorities for program utilization, coordinated waiting lists for caregiver services and integrated sliding-fee scales.

- In Pennsylvania, the National FCSP has enabled the state to expand the population served in its state-funded program to serve caregivers, other than family, who support care recipients who do not live with them.
- In the State of Washington, the state-funded Family Caregiver Support Program offers respite to all caregivers who provide care to adults aged 18 and older who have a functional disability. A common screening instrument is used for all consumers and caregivers seeking services. When appropriate, a referral is made to the AAA for provision of caregiver supports, including respite, under the OAA FCSP.

*The **Pennsylvania** FCSP limits the financial reimbursement to caregivers to a maximum of \$500 per month and allows an additional one-time reimbursement for home modifications and assistive devices.*

Despite the broad array of respite services that states have developed, all caregivers who need and want respite are clearly not able to obtain the kind of assistance they need, where they need it, when they need it. The demand for respite care continually challenges states to weigh the benefits of serving more people versus providing more services to a more limited number of caregivers. If any limits are set in the FCSP, those limitations are most likely to apply to respite care. Some programs impose dollar or time limitations on the amount of respite caregivers may obtain. Programs also may decide to limit the number of hours or days of respite that a caregiver may receive during a set period of time. Modest cost sharing requirements also may be imposed when the caregiver's income or the income of the care receiver exceeds a set amount. The rules governing such limitations may be set at the state or AAA level.

States may also need to set a limit on the percent of funds that may be spent on respite services in order to ensure that the FCSP has sufficient resources to provide the full array of caregiver supports. For instance, the State of Washington limits spending on respite care in the FCSP to 35% of total funds. Limitations may also reflect a desire to ensure that the services of the FCSP do not duplicate services which may be provided under another funding source. For example, if respite care is provided under a Medicaid waiver program, the FCSP may decide that caregivers cannot receive respite under the

¹⁵ New Jersey EASE is the "Easy Access, Single Entry" system operated in each county of the state to provide access to the array of available home and community based services. AAAs serve as the lead NJ EASE agencies.

FCSP if they are able to obtain the service under the waiver or that respite under the FCSP will be used to supplement, but not replace, respite under the waiver.

The availability of respite care may also be impacted by circumstances that affect the entire service system. For instance, provider shortages are likely to impact the FCSP. In rural areas, the supply of respite providers may be limited or non-existent. Creative solutions are needed to overcome these problems. "Mobile adult day care" which is available to certain rural communities in Georgia on set days each week is one such solution. A consumer-directed approach that allows caregivers to hire neighbors and friends as respite providers rather than requiring them to use an agency or particular setting is another.

5) SUPPLEMENTAL SERVICES

Supplemental services are "other services, as defined by states, to support the needs of caregivers."¹⁶

The supplemental services component of the FCSP allows for creativity and responsiveness to specific caregiver needs. Each local program has the opportunity to develop this component as a tailored response to the particular needs of caregivers in their jurisdiction. The list of potential service options is very wide. Some states have included home modifications (e.g., installation of grab bars or ramps), emergency services, home visits by nurses, assistive technology, and equipment loans of items such as walkers, wheelchairs, crutches, or adaptive equipment.

FCSPs should ensure that the services proposed for inclusion as supplemental services do not duplicate services available to caregivers and consumers through other programs. Learning about the array of services available through the state's HCBS programs is therefore an important first step in determining the appropriate package of supplemental services.

This category of services, like respite care, is one where program policies may limit the amount of services or funds provided to each caregiver. Cost sharing policies and eligibility criteria that ensures that the FCSP does not duplicate services available through other programs are important considerations.

PART III SUGGESTIONS FOR STATES REGARDING THE SERVICE PACKAGE

State Units on Aging and Area Agencies on Aging have an incentive to promote the Family Caregiver Support Programs as a critical component of the home and community based services system. Without sufficient attention to the needs of caregivers, older persons in need of long term care will be more likely to lose the battle to stay in the community as their care needs increase. SUAs and AAAs, then, must look critically at the FCSP to ensure that it is being developed as an important component of the HCBS system and that crucial connections are made.

This section provides guidance to SUAs and AAAs in the form of **critical questions** about the service package. A response to each question is provided through recommended **design approaches** and a list of **optional implementation strategies** from which programs may choose. States are encouraged to identify the questions that are most critical to the development of their own FCSP, and to select design approaches and implementation strategies most suited to their needs.

Critical Questions

¹⁶ Op. cit.

1. How easy is it for caregivers and care recipients to access needed information, assistance, services and supports?
2. How effective is the FCSP in reaching underserved populations?
3. How are the needs and preferences of caregivers identified?
4. How will the individual caregiver's need for support be determined?
5. Are FCSP services responsive to the diverse and changing needs of caregivers?
6. Are FCSP services provided in a culturally appropriate manner?
7. Are caregivers' support needs recognized and addressed by HCBS programs?
8. How are FCSP services coordinated with other caregiver support and HCBS programs?

Design Approaches and Optional Implementation Strategies

1. **How easy is it for caregivers and care recipients to access needed information, assistance, services and supports?**

Design Approach

Ensure that information resources for caregivers and consumers are readily available when and where caregivers are most likely to seek assistance.

North Carolina's logo - representing the "circle of care" present in the FCSP - will be used on all state and AAA publications, as well as local providers' materials. The accompanying tagline - "Completing the Care" - is meant to convey that the FCSP "completes the circle" by helping caregivers reach their full potential.

Optional Implementation Strategies

- ✓ Set aside administrative funds at the state level and/or pool AAA administrative funds to support a statewide **information/promotion campaign**.
- ✓ Develop a readily identifiable **logo and message** that provides consistent information on the FCSP.
- ✓ Craft easy-to-read and readily identifiable **NFCSP materials** that provide a basic understanding of services, programs, and assistance.
- ✓ Establish a **statewide toll-free number** to provide easy access for long distance caregivers.
- ✓ Develop a **call-routing system** that transfers callers to the appropriate local agency to obtain information on service availability in their community and to prevent callers from having to make multiple calls to obtain needed information.
- ✓ Establish a **24-hour automated telecommunication system** or staff information lines in the evenings and on weekends to accommodate working caregivers.
- ✓ Post **information on the internet** and set up a system that allows caregivers to email their questions and information requests to the program, providing a gateway that is available 24/7. Information technologies may be particularly suited to reaching people in rural communities and long-distance caregivers, and can be used to provide information and support to persons who are homebound and their caregivers.
- ✓ Develop **on-line education** programs or chat rooms.
- ✓ Develop informational materials or **video and audio tapes**.

- ✓ Make video and printed materials available through **churches, libraries and community organizations.**

In New Jersey, a statewide system called Easy Access, Single Entry (NJ EASE) uses one toll-free telephone number to connect callers to information about the range of services available in their own communities.

Design Approach

Develop and/or enhance the information delivery system so that caregivers seeking information about services for the care receiver, as well as support services for themselves, are assured *seamless access* to information about the entire spectrum of HCBS and FCSP programs.

Optional Implementation Strategies

- ✓ **Coordinate the FCSP with existing I&R/A programs** to provide information and access to the caregiver support program through the same information line that is used to obtain information on a wide range of services for older persons.

In Massachusetts, potential consumers of aging services initially contact the state's toll-free information line, 1-800-AGE-INFO. Callers are then routed to the AAA/ASAP (Aging Service Access Point) that serves their area for an assessment (including completion of a Caregiver Intake form when appropriate) and service coordination

- ✓ **Identify barriers** older consumers and caregivers currently face in accessing information on the range of home and community based services. Such assessments can be done statewide or at the AAA level.
- ✓ Ensure that information on the FCSP is provided via the designated **"single entry point"** in each community (if available), or with all the entry points for HCBS when there is no designated single entry point.
- ✓ Develop and deliver **staff training** and provide informational materials on the FCSP to the I&R/A and the entry points for all HCBS programs. Training of FCSP staff is also needed to ensure understanding of both the I&R/A program and HCBS. A cross-training approach may be appropriate to encourage information sharing and coordination.

2. How effective is the FCSP in reaching underserved populations?

Design Approach

Target specific resources and develop special initiatives for reaching underserved populations.

Optional Implementation Strategies

- ✓ Analyze population data available from the Census, data gathered via surveys or focus groups, and/or statistics on persons served in the state's public pay programs to **identify population groups that have typically been underserved** (e.g., ethnic and minority groups, rural caregivers). Data analysis may be done at the state level or SUAs could require AAAs to do their own data analysis.

- ✓ Invite representatives of ethnic and minority groups and organizations, as well as agencies that serve grandparents and/or people in rural areas, to participate in a **special task force** or already-existing advisory groups to identify outreach approaches and service needs of underserved population groups.
- ✓ **Establish relationships** with business and civic groups, with faith-based organizations, with ethnic and culture-specific groups to reach their constituencies.
- ✓ Form statewide and/or community **advisory groups, task forces, or coalitions** to promote outreach to specific groups.
- ✓ Ensure the **participation of diverse caregivers** and care recipients in caregiver/HCBS task forces and groups that serve in an advisory capacity to the FCSP and other HCBS programs.
- ✓ Require the AAAs to address in their area plans the **specific efforts** they will undertake **to reach underserved caregivers** and ensure that their programs are culturally competent. Methods AAAs might employ to ensure responsiveness of the FCSP to caregivers from diverse cultures and ethnic groups may include:
 - ✓ Employing **bilingual and ethnically/racially diverse staff** representative of the caregivers in their jurisdictions.
 - ✓ **Contracting with community organizations** that serve particular ethnic or cultural groups to become providers of caregiver support.
 - ✓ Providing **cultural competency training** to all staff.
- ✓ Use FCSP administrative funds to support **special initiatives for reaching underserved populations**. Provide grant funding to local agencies to develop innovations in caregiver support for particular groups.
- ✓ Craft **messages about the FCSP for specific target groups**, e.g., persons who do not recognize themselves as caregivers, ethnic and cultural minorities.

3. How are the needs and preferences of caregivers identified?

Design Approach

Identify caregivers' needs and preferences regarding caregiver supports.

Optional Implementation Strategies

- ✓ Develop and **conduct a survey or convene focus groups** of caregivers (including actual and potential users of the FCSP). A statewide survey of caregivers may be conducted by the SUA, or the SUA may require each AAA to identify caregivers' needs through a survey or caregiver focus groups.
- ✓ Develop **special surveys and/or focus groups** targeted to specific racial/cultural/ethnic groups to identify unique preferences and needs for caregiver supports.
- ✓ Create an **advisory committee** with caregiver representation for the FCSP at the state level and/or require each AAA to develop advisory groups.
- ✓ **Analyze the information** collected in the FCSP annually (or more frequently) to identify the support services most frequently requested by caregivers.
- ✓ Develop and administer a **caregiver satisfaction survey** to obtain information regarding caregivers' satisfaction with the amount and type of supports they receive

through the FCSP, how and when services are delivered. The survey can also be used to identify unmet needs.

- ✓ **Use the information** obtained via surveys, focus groups, advisory group members, program data, and caregiver satisfaction surveys to identify needed changes in the service package, including the need to add specific supports to the supplemental services category.

4. How will the individual caregiver's need for supports be determined?

Design Approach

Decide how and by whom caregivers' needs will be assessed.

Optional Implementation Strategies

- ✓ Identify the essential information needed to determine a caregiver's need for supports and whether a standardized **caregiver assessment** instrument will be used by the FCSP. Select or develop an assessment instrument, or add specific questions to an already existing instrument used to determine the need for aging/HCBS services.
- ✓ Decide on the circumstances under which a caregiver's need for supports will be **formally assessed** (e.g., to determine the need for respite or supplemental services).
- ✓ Determine whether (1) the caregiver assessment instrument will be used solely by the FCSP or (2) elements of the **caregiver assessment** will be **incorporated into the comprehensive assessment** instrument used by the HCBS system.
- ✓ Determine the need to create a new position within the FCSP or provide specialized training to current **staff to conduct caregiver assessments** and/or assist caregivers to identify their support needs.

5. Are FCSP services responsive to the diverse and changing needs of caregivers?

Design Approach

Develop FCSP services that respond to individual caregivers' current and changing needs.

Optional Implementation Strategies

- ✓ Develop **working relationships** with organizations such as the Alzheimer's Association, mental health agencies, religious and ethnic organizations and refugee centers.
- ✓ **Contract with organizations** such as those listed above to be providers of caregiver supports (including counseling, support groups and caregiver training) for particular segments of the caregiver population.
- ✓ Develop **referral protocols** between the FCSP and providers of counseling such as mental health organizations to ensure that caregivers whose support needs exceed the counseling services provided by the FCSP receive needed assistance.
- ✓ Develop **caregiver training** that is responsive to the education levels, cultures, languages and ethnic groups represented in the community, as well as the different levels and types of care provided by caregivers. Involve ethnic, cultural, religious and other community groups in the development and provision of such training.

- ✓ Consider using **volunteers** to provide counseling and run support groups. If volunteers are used, make sure they are representative of the diversity found in the community.
- ✓ Use **video and audio tapes, the internet and local public radio and television stations** to provide counseling, support and training for caregivers at times and locations that respond to caregivers' needs and preferences.
- ✓ Ensure that **respite care is provided in a variety of settings** (e.g., in the home, adult day care, nursing facilities) and is responsive to caregivers' unique circumstances (e.g., giving caregivers vouchers, permitting caregivers to accumulate respite hours rather than requiring a set schedule, allowing caregivers to hire other relatives or friends as respite providers).
- ✓ Develop the supplemental services component of the FCSP to **fill gaps** in the service package that cannot be addressed through other programs (e.g., if home modification is identified as a need, will caregivers' needs be met through a Medicaid HCBS program?).

6. Are FCSP services provided in a culturally appropriate manner?

Design Approach

Develop services that are tailored to the needs of caregivers from diverse cultures and backgrounds.

Optional Implementation Strategies

- ✓ Develop **partnerships** at the state and local level with agencies and community organizations that serve specific population groups (e.g., persons with developmental disabilities, children, African Americans, individuals who are lesbian/gay/bisexual/transgendered).
- ✓ **Conduct surveys and/or convene focus groups** with specific population groups (e.g., minority elders, rural elders, older persons providing kinship care) to identify the kinds of caregiver assistance they need and preferences for service delivery (e.g., having services provided by a known community agency that historically has served the particular group).
- ✓ Offer caregiver support services in **settings** (such as churches, service centers, and other community meeting places) that are **familiar to and comfortable** for specific racial/ethnic/cultural groups of caregivers.
- ✓ **Contract with agencies/organizations** to become FCSP providers for specific target groups (e.g., ethnic and cultural community agencies, minority-owned provider organizations, agencies that serve grandparents).
- ✓ Require AAAs and other agencies/organizations that provide FCSP services to **train staff and volunteers in cultural competence** issues tailored to the needs of caregivers in each community.
- ✓ Require AAAs and agencies/organizations that provide FCSP services to ensure that **staff and volunteers reflect the cultural, ethnic, racial and language diversity** of the caregivers in each community.
- ✓ Develop **specific initiatives** to meet the caregiver support needs of particular racial/ethnic/cultural groups. Use FCSP administrative dollars and/or encourage

AAAs to pool some of their FCSP funding. Competitive grants may be provided to AAAs and/or agencies/organizations that serve target populations.

7. Are caregivers' support needs recognized and addressed by HCBS programs?

Design Approach

Engage in ongoing dialog and information exchange with the HCBS system to ensure recognition of and responsiveness to caregivers' support needs, and understanding of the FCSP.

Optional Implementation Strategies

- ✓ **Develop information/training** about the important contributions of caregivers in helping HCBS consumers remain in the community, the support needs of caregivers, and the FCSP.
- ✓ **Disseminate information and/or provide training** to the HCBS system, targeted to intake workers, case managers, program administrators and HCBS service providers.
- ✓ Ensure that the **FCSP is involved in decisions** about whether to incorporate caregiver assessment into the comprehensive assessment instrument used by the HCBS system, and that such an instrument collects appropriate and sufficient information to determine the need for FCSP services.

8. How are FCSP services coordinated with other caregiver support and HCBS programs?¹⁷

Design Approach

Develop relationships and coordinate with state-funded caregiver support programs and HCBS programs in the state.

Optional Implementation Strategies

- ✓ Develop **protocols for information sharing and referrals** between the FCSP, other state caregiver programs and HCBS programs to ensure that the needs of care recipients and caregivers do not fall between the cracks.
- ✓ Develop **procedures for information sharing and coordination** when the caregiver is served by the FCSP and the care receiver gets services through the HCBS program.
- ✓ Develop a **single entry point** for all caregiver supports, regardless of the funding source. If there are multiple entry points for caregiver services, share information (on target population served in each program, eligibility requirements, and services provided) and develop referral protocols.
- ✓ Develop a **single caregiver intake form** to determine the need for caregiver supports and a referral protocol to ensure that caregivers are referred to the most appropriate program for services.
- ✓ Develop criteria regarding when a referral will be made to other caregiver support or HCBS programs to **supplement or substitute for FCSP** services.

¹⁷ This questions focuses on coordination issues in relation to the service package. The second paper in this series will discuss coordination and service continuity more broadly.

APPENDIX
Selected State Profiles

Selected State Profiles

Introduction

The Family Caregiver Support Programs in nine states - Georgia, Massachusetts, Minnesota, New Jersey, Ohio, Oregon, Pennsylvania, Washington and Wisconsin - are profiled in this document. These states were identified by the Expert Panel as states that are developing their caregiver programs within the broader home and community based service system.

The State Profiles that follow briefly describe how each of the nine states addresses:

- Caregiver access to services and supports;
- Coordination between the FCSP and other caregiver programs that may exist in the state, as well as with HCBS programs; and
- Outreach to underserved populations.

As part of this project, NASUA will convene a series of teleconferences with all states to expand the current Profiles and incorporate more states' experiences.

State Profile

Georgia

Georgia's Division of Aging Services is integrating the Family Caregiver Support Program (FCSP) into its existing framework of Home and Community Based Services (HCBS) including Older Americans Act, Medicaid Waivers and State funded services. The Division is reviewing policies and procedures for client and caregiver eligibility and coordinating services for consumers from all available sources. In particular, the Georgia FCSP will be working to ensure that caregivers of clients enrolled in Medicaid waiver programs are appropriately referred for Title III-E services.

In Georgia, consumers and their caregivers access services through a single entry point called Gateway located in each of the 12 Area Agencies on Aging (AAA). AAAs manage all activities related to Information and Referral as well as the maintenance of waiting lists. At the AAA, specialized staff receive inquiries regarding services and resources. In situations requiring a referral for services, AAA staff will use an electronic database to conduct a guided screening to assess the caller's needs and determine which programs are appropriate to meet those needs. A referral is then made to the appropriate agency and program. In situations where the need for FCSP service has been identified by the provider (e.g., by a Waiver provider), the State Unit on Aging (SUA) is working with AAAs and the state aging network to assure that a referral process is in place. When referrals are made, the information gathered during screening is validated by a comprehensive assessment, which includes the Determination of Need Revised (DON-R) instrument, which assesses ADLs, IADLs, and unmet need for care, as well as the Montgomery-Borgatta Caregiver Burden Scale.

Most of Georgia's 159 counties are rural. As a result, there has always been a focus on serving rural populations. In addition, specific AAAs with large Hispanic populations have developed outreach materials in Spanish and disseminated them within their regions.

Contact: Cliff Burt, GA Division of Aging Services, (404) 657-5336, gcburt@dhr.state.ga.us.

State Profile

Massachusetts

Massachusetts has two entities responsible for delivering services to seniors at the local level: state-funded Aging Service Access Points (ASAP) and federally-funded Area Agencies on Aging (AAA). In all but a few jurisdictions, the ASAP and AAA are located within the same agency.

There has been a great deal of close collaboration between staff of both ASAPs and AAAs in meeting the needs of consumers and caregivers. ASAPs administer respite services through the Massachusetts Home Care and Respite Care Programs, which are entirely state-funded. Massachusetts has not placed a limit on the number of hours of respite that may be authorized in a month through the Respite Care Program. However, ASAPs receive a monthly reimbursement for the number of clients served and they have to manage against that budget.

AAAs administer services funded through the OAA program and, as a result of the National Family Caregiver Support Program (NFCSP), recently employed positions with varied titles such as "Caregiver Specialist," "Caregiver Trainer" or "Caregiver Liaison." Under the Massachusetts FCSP, ASAPs use state funds to employ staff referred to as "Elder Care Advisors" who provide case management services to consumers and caregivers, regardless of income levels, for a limited period of time.

A number of ASAPs are also in the process of developing consumer-directed service models, which allow an elder or caregiver to choose, hire, and supervise their service provider with the fiscal support, planning guidance and oversight of the ASAP. AAAs are also providing families with consumer choice through "service scholarships," which allow caregivers to "audition" a service (e.g., respite) without spending their own money. Preliminary reports show that in most cases, the family then decides to pay privately for the service after seeing the help that it can provide.

Potential consumers of aging services make initial contact through the state's toll-free number, "1-800-AGE-INFO". Callers are routed to the ASAP/AAA agency in their area for assessment and service coordination. ASAPs assess potential recipients of services with a comprehensive long term care needs assessment. A Caregiver Intake Form, which is less detailed than a full assessment, is being developed and will be used when a caregiver needs services.

Massachusetts is developing several initiatives to reach underserved populations and groups that have not traditionally participated to a great extent in such programs. Focus groups convened around the state found needs driven by local concerns, including non-English speaking populations, Grandparents raising grandchildren and gay/lesbian caregivers. As a result, AAAs have provided funding to community based organizations to develop several initiatives including: support groups for non-English speaking persons, foreign language I & R materials (e.g., Russian and Chinese) and support groups for gay and lesbian caregivers.

Contact: Michael Banville, MA Executive Office of Elder Affairs, (617) 727-7477, michael.banville@state.ma.us.

State Profile

Minnesota

In addition to National Family Caregiver Support Program (NFCSP) funds, Minnesota's caregiver system is supported by several funding sources, including: Elderly Waiver funds; the state-funded Alternative Care Program; the Respite Grant Program; Community Services Grants; United Way; cash grants from counties; The Robert Wood Johnson "Faith in Action" Program; an AoA Alzheimer's Grant; and local fund raising efforts.

Consumers and caregivers can go to any access point in the HCBS system to gain access to services available to them. Because many of these access points are providers of services, Minnesota has established "cross-system linkages" for referrals, information and service coordination for caregivers. Consumers and their caregivers are assessed through a Pre-Admission Screening process called "Long Term Care Consultation" done by the county or by service providers of home-delivered meals, transportation, chore services or homemaking. The Board of Aging is also working with the Minnesota Medical Association to get physicians' offices to agree to conduct these assessments as well.

Through Title III-E funding, special efforts have been developed to reach underserved immigrant and minority populations, especially in the metropolitan Twin Cities area. In addition, through state funded Community Services Grants, Minnesota gives funding to specific providers of caregiver services (e.g., respite, caregiver training and education, support groups), including respite for Latino, Southeast Asian, and Native American elders.

Contact: Jane Vujovich, MN Aging & Adult Services Division, (651) 882-6262, Jane.Vujovich@state.mn.us.

State Profile

New Jersey

As part of its Administration on Aging (AoA) Innovative Caregiver Grant, New Jersey will be integrating Family Caregiver Support (FCSP) program services with Medicaid Waiver and state-funded programs for caregivers under the NJ EASE (Easy Access, Single Entry) system for senior services. New Jersey's state-funded caregiver programs include the Statewide Respite Care Program, Alzheimer's Day Service Program, In-Home Caregiver Education Program, Jersey Assistance for Community Caregiving and Caregivers Assistance Program.

Area Agencies on Aging (AAA), the lead NJ EASE agencies in each county, are required to identify caregiver needs and develop strategic plans for addressing these needs and for integrating local programs for caregivers with the NFCSP. Coordination for all caregiver programs is the responsibility of the AAAS, under the umbrella of the NJ EASE system.

New Jersey consumers and their caregivers enter Home and Community Based Services (HCBS) through one of the 21 NJ EASE sites located in the county-based AAAs. There, the needs of both consumers and caregivers are assessed using New Jersey's comprehensive assessment tool (CAT). This tool includes a brief caregiver interview. One of the tasks to be completed under the AoA grant is development of a comprehensive caregiver assessment tool that will focus on their unique needs. This caregiver assessment, once computerized, will become an integral part of the CAT, along with a caregiver screening tool and an integrated family care plan.

Under the AoA grant, the state will also develop a culturally/linguistically competent caregiver service system. To achieve this goal, New Jersey has established an advisory council comprised of members representing New Jersey's diversity. This advisory council will be looking at how sensitive and accessible New Jersey's services are to the needs of underserved populations including minority and ethnic groups. The council will review the caregiver assessment tool being developed to determine whether the questions are acceptable for diverse populations and if any questions pose barriers for caregivers in certain cultures. In addition, FCSP materials will be translated (e.g., Russian and Spanish), a training curriculum will be developed for county staff and a new web site is under development.

Contact: Barbara Fuller, NJ Division of Senior Affairs, (609) 943-3363, barbara.fuller@doh.state.nj.us.

State Profile

Ohio

The Ohio Department of Aging (ODA) administers three HCBS programs to serve the needs of the elderly: the Medicaid Waiver program, "PASSPORT"; the Alzheimer's Respite program; and the Family Caregiver Support Program (FCSP). ODA sets consistent guidelines for the agencies that administer PASSPORT at the local level. The agencies (AAAs and Catholic Social Services of Sidney) conduct assessments and coordinate services in accordance with the care plan that is developed.

For the state's Alzheimer's Respite program and the FCSP, the ODA sets general policy and monitors integration and service provision while permitting AAAs to determine how intake and assessment will be handled. AAAs may adopt either (1) a centralized model in which all intake and assessment is conducted by the AAA or (2) a provider based model in which the provider agency is responsible for assessment and service provision. Approximately 75% of the AAAs have adopted a centralized model, generally referred to as the Care Coordination Program. These AAAs utilize case managers and a designated phone line to provide access to the PASSPORT program and the FCSP as well.

ODA has developed written policy that allows AAAs to decide how services are coordinated under the FCSP. This policy states that AAAs can either directly provide service (excluding respite), provide the FCSP under contract with a service provider or coordinate the FCSP with another organization (MRDD, Alzheimer's Association, Kinship Navigator) that is providing that same service.

Some AAAs have structured culturally relevant caregiver training and information in their areas. Additionally, ODA has encouraged AAAs to make special efforts to reach out to working caregivers who may not have traditionally participated in aging network programs.

Contact: Richard LeBlanc, OH Department of Aging, (614) 466-7967, dleblanc@age.state.oh.us.

State Profile

Oregon

Oregon Seniors and People With Disabilities (SPD) has integrated the Family Caregiver Support Program (FCSP) with their other programs serving seniors. In Oregon, the 20 multi-county Area Agencies on Aging (AAA) act as the central intake, assessment and service coordination point for seniors and their caregivers.

Consumers and their caregivers access SPD services by calling the AAA. A uniform assessment, that includes a look at caregiver needs, is completed by a AAA staff member. Services are then coordinated through one or several of the state's funding sources (e.g., the FCSP) and may be provided by either the AAA or a subcontractor identified by the AAA.

Respite and related services may be provided through the state's Lifespan Respite Network or through the FCSP. The Lifespan Respite Network was begun in 1997 to assist in the development of caregiver partnerships to address caregiver issues at the local level and looks at these issues across the life span regardless of age or special need.

In the future, Oregon may consider a brokerage model of services for family members in the FCSP that is similar to one being implemented in programs for persons with developmental disabilities. Under this model, families would receive a set dollar amount, based on the need of the person receiving care, for services such as personal care, respite and training.

Oregon has developed a web site for caregivers, www.oregoncares.org, and a toll-free number (1-866-219-7218) consumers may call with questions about caregiving and to obtain information about respite, financial and legal planning and health care options.

Oregon's goal is to provide access to respite and related services in all of the state's 36 counties by 2003, including rural and economically disadvantaged areas of the state. The state is partnering with programs that are focusing on the same goal. One such program is "The Powerful Tools for Caregiving" training program. Utilizing funds from The Robert Wood Johnson Foundation, Northwest Health Foundation and the Good Samaritan Foundation, the mission of "The Powerful Tools for Caregiving" project is to support family caregivers of older adults in a way that enhances their well being as they care for others.

Outreach to the Native American Senior population is also happening as the result of partnerships between five of Oregon's Title VI grantees and SPD. As Title VI grantees develop caregiver support programs for their elders and family members caring for them, SPD plans to offer the Title VI directors access to the family support coordinator (the SUA contact responsible for FCSP development and oversight in the state) for technical assistance and the use of SPD caregiver information and resources. SPD will, in turn, request input from Title VI grantees regarding the content of Native American related sections of SPD's caregiving web site.

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State Profile

Pennsylvania

Since 1992, the Pennsylvania Department of Aging (PDA) has operated its state Family Caregiver Support Program (FCSP) as an integral part of its Aging Home and Community Based Services (HCBS) system. This system includes the HCBS Medicaid Waiver, the OPTIONS Program and other home and community based services. OPTIONS provides HCBS to elderly consumers funded by Pennsylvania Lottery dollars and Aging Block Grant funds. The funds provided by the National Family Caregiver Support Program (NFCSP) have allowed the PDA to enhance the state's FCSP by expanding services to include caregivers and care receivers who are not related or living in the same household and older relative caregivers of young children who do live together.

As with all aging programs in Pennsylvania, the FCSP is administered locally by one of 52 Area Agencies on Aging (AAA) in each Planning Service Area (PSA). The AAA acts as the intake point for consumers and caregivers needing services. Care managers in each AAA conduct the assessment and assist the family and care recipient in determining the services that are most appropriate for their situation.

The PDA FCSP provides assessment, care management, benefits counseling, caregiver counseling, training and education, and access to support groups. The FCSP can provide a monthly financial reimbursement of up to \$500 (though the aggregate caseload average must not exceed \$300 per month). These funds can be used for any services that can be justified as related to caregiving, such as respite, durable goods or medical supplies. A one-time reimbursement of up to \$2,000 for home modifications and assistive devices is also available. Each consumer/family tailors services to fit their own needs. Caregivers are reimbursed for expenses, but may NOT be paid for performing caregiving tasks.

The PDA has received an Administration on Aging (AoA) FCSP Grant (Linkages to Special Populations and Communities) to implement the "Elderly Caregivers of Adults with Disabilities" project. The project will serve age 60 and older caregivers of relatives aged 19 to 59 with mental retardation and/or developmental disabilities. This three-year grant (9/30/01 - 9/29/04) is being piloted in two counties, one in the east and one in the western part of the state. It is modeled after the state FCSP and it is hoped that, following the grant period, sufficient support and/or additional funding will become available to replicate and continue the program statewide.

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State Profile

Washington State

The state of Washington has three programs that address the needs of caregivers: (1) the state Respite Care Program targets family and other unpaid caregivers assisting adults (18+) with a functional disability and has been in operation since 1989; (2) the state Family Caregiver Support Program (FCSP) was established in 2000 and extends additional supports to all caregivers; and (3) the National Family Caregiver Support Program (NFCSP).

The NFCSP and the Respite Program are administered by Aging and Adult Services Administration (AASA) at the state level and administered at the local level by 13 Area Agencies on Aging (AAA). AAAs are the access points for family caregivers seeking information, assistance and services. In addition, AASA's six regional Home and Community Services (HCS) offices serve as an entry point for the care recipient to home and community based services (HCBS). This process naturally includes the caregiver but has historically not been focused on meeting caregiver needs.

With a strong community-based service network, HCSs and AAAs work closely in serving the long-term care population. A standardized comprehensive assessment (CA) tool is used to evaluate the needs of the care recipient. The CA, currently under revision, will soon include an enhanced section devoted to family caregiver needs and issues. A new effort is the implementation of a caregiver screening tool at the HCS entry point designed to increase recognition of family caregiver needs and to speed up appropriate referrals to the new FCSP.

In Washington, each AAA has designated a FCSP that responds to the needs of its caregiving community. While each program offers the full array of services available through the NFCSP, the services are delivered differently depending on the area of the state.

The AASA has not set limits on caregiver services. Because the AAAs have operated the state funded Respite Care Program budget for the past 13 years, it is felt that they have the expertise and experience to allocate resources/services to meet caregivers' needs. Some AAAs are experimenting with a limit on what families may spend annually (either a \$500 or \$1,000 annual limit) from the supplemental services category.

During Washington's seven-year federal Alzheimer's Demonstration Program (funded by HRSA and AoA), AASA and the participating AAAs learned a great deal about reaching underserved populations. AAAs are required to specify how they will reach underserved populations in their area plans. Additionally, Washington is using a majority of the NFCSP administrative funds to provide one-year grants to pilot projects designed to serve three population groups: ethnic communities; geographically isolated/rural areas; and ethnic/kinship caregivers. A competitive Request for Proposal for "Innovations in Family Caregiver Support" was developed and disseminated broadly. Recently, the grant application review process determined the ten projects that AASA will fund beginning in July 2003.

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State Profile

Wisconsin

Wisconsin's Bureau of Aging and Long Term Care (LTC) Resources has developed policy detailing how FCSP services are to be integrated with other HCBS and/or aging programs:

"To assure coordination of caregiver services in the county, the aging unit shall convene a minimum of one joint planning meeting with other local providers who currently provide support services to family caregivers. The aging unit shall coordinate the activities under this program with other community agencies and voluntary organizations providing services to caregivers. Funding under this program gives aging units an opportunity to advocate with other provider agencies to expand and enhance existing services to better meet the needs of family caregivers. Every effort should be made to integrate or closely coordinate the Family Caregiver Support Program and the Alzheimer Family Caregiver Support Program, preferably with other Title III programs."

The SUA contracts with six Area Agencies on Aging (AAA) located throughout the state. Four of the AAAs contract with the county's Office on Aging to provide services directly or by subcontract with local providers. The remaining two AAAs each serve a single county.

In all jurisdictions, consumers and caregivers in need of services contact their local county office on aging "Aging Resource Center", which is responsible for: identifying service needs and making referrals for assessment and service coordination. If a determination is made that the consumer is eligible for the Waiver, a referral is made to the Waiver provider. In the unlikely event that the consumer contacts the Waiver provider first to obtain services, these providers are well informed and would refer consumers to the NFCSP where appropriate.

Wisconsin has carefully defined respite and supplemental services and has also established limits for each. Respite care is defined as "temporary" (not more than seven consecutive days, limited to 14 days in a calendar year) to provide relief or rest for caregivers. Respite can be provided as in-home care, adult day care or institutional care provided overnight or on an intermittent, occasional or emergency basis. Supplemental services are provided on a limited basis (not more than one time per week or a total of eight hours per week) to complement care provided by caregivers. These services are not to exceed 20% of the county allocation.

Requirements for reaching underserved populations apply to all aging programs. The NFCSP has provided additional funds for outreach and development of information materials.

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